Health-Related Quality of Life at Age 10 Years in Very Low-Birth-Weight Children With and Without Threshold Retinopathy of Prematurity

CRYO-ROP Cooperative Group*

**Objective:** To describe parental perspectives on health status and health-related quality of life (HRQL) at age 10 years in children with birth weights less than 1251 g who participated in the multicenter Cryotherapy for Retinopathy of Prematurity (CRYO-ROP) study.

**Methods:** In 244 participants in the randomized CRYO-ROP trial and 102 CRYO-ROP participants who did not develop ROP, the Health Utilities Index (HUI) system was used to characterize health status for the following 8 attributes: vision, hearing, speech, ambulation, dexterity, emotion, cognition, and pain. Using a utility formula, HRQL was determined for each child on a scale from 0.0 (dead) to 1.00 (perfect health).

**Results:** The proportion of the ROP-randomized group with limitations in 4 attributes or more was 20.6% compared with 2.0% for the no-ROP group. Within the ROP-randomized group, the proportion of “sighted” children with limitations in 4 attributes or more was 6.4% vs 46.5% in the “blind/low vision” group. The median HRQL score for the ROP-randomized children was lower than for the no-ROP children (0.72 vs 0.97, \(P<.001\)); the median HRQL score for the sighted-randomized children was 0.87 vs 0.27 for the blind/low vision children (\(P<.001\)).

**Conclusions:** Threshold ROP was associated with functional limitations in health attributes and reduction in HRQL scores at age 10 years. Furthermore, among children who developed threshold ROP, a greater reduction in HRQL scores was found among children with a poor visual outcome compared with those with better sight.

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**Protocols for Premature Birth:**

Pretterm birth may have a lifelong influence on general health, academic abilities, and behavior. In earlier studies, these conclusions were based on standard psychometric measures and histories elicited from parents and teachers. More recently, Saigal and colleagues have used a multiattribute approach, the Health Utilities Index (HUI) system, to report the health status and health-related quality of life (HRQL) in a cohort of extremely low-birth-weight (ELBW, <1000 g) children at age 8 years, compared with a cohort of full-term children of the same age. In that study, the health status was determined retrospectively from objective psychometric measures, and a utility equation was applied based on preferences from a random sample of 194 parents of school-aged children. Results indicated that the mean HRQL score was significantly lower in the ELBW group than in the reference group, with higher variability of scores in the ELBW group. Particularly notable in the ELBW group were limitations in cognition (58%), sensation (vision, hearing, and speech) (48%), mobility (21%), and self-care (17%) compared with 28%, 11%, 1%, and 0%, respectively, for children in the full-term reference group. A significantly higher proportion of the ELBW children had limitations in multiple attributes.

Retinopathy of prematurity (ROP) is a significant and relatively common morbidity of extremely preterm birth and is sometimes associated with other adverse perinatal events such as periventricular leukomalacia, intraventricular hemorrhage, bronchopulmonary dysplasia, and necrotizing enterocolitis as well as visual impairment. However, comparisons of HRQL in preterm infants with and without ROP have not been reported.

Recently, 247 children with birth weights less than 1251 g who had threshold ROP during the neonatal period and who participated in the randomized trial of cryotherapy for severe (threshold) ROP (CRYO-ROP) returned for a 10-year follow-up. As part of the 10-year examination, an interview of...
parents/guardians was conducted to assess the health status and HRQL of these children. During the same period, identical 10-year follow-up examinations were conducted on a reference cohort of 102 children who were also participants in the CRYO-ROP study at 1 of the 23 study centers, who had birth weights less than 1251 g, but who did not develop ROP in the neonatal period.20,21

The purpose of this article is to provide HRQL results for children in the cohort that developed threshold ROP, as well as for a concurrent reference group of children who did not develop ROP. We hypothesized that children in the threshold cohort would have lower HRQL scores than the generally healthier children with larger birth weights in the reference group, and that children whose threshold ROP led to blindness or very low vision would have lower HRQL scores than those children with threshold ROP in whom good visual function was preserved.

**METHODS**

**SUBJECTS**

Subjects were 2 groups of 10-year-old children who had birth weights less than 1251 g and who were participants in the multicenter CRYO-ROP study, in which subjects were enrolled from January 1, 1986, through November 30, 1987. One group was the 255 surviving children (291 were initially enrolled at 23 centers) who had developed threshold ROP (defined as stage 3 ROP in zone 1 or in zone 2 with 5 continuous or 8 cumulative sectors of fibrovascular proliferation in the presence of plus disease)22 during the neonatal period and who were participants in the randomized trial of cryotherapy. Although detailed neurological information is unavailable for these subjects, data obtained at the 3 1/2- and 8-year examinations indicated that functional limitations were present in many of the children who had developed threshold ROP.21,22 Two hundred forty-seven (96.8%) of the 255 surviving children in this group returned for the 10-year follow-up examination.19 The Health Utilities Index Mark 3 (HUI3)22 questionnaire was administered to the parents of 244 and complete answers to the HUI3 questionnaire were obtained from parents of all but 1 of the children. The second group (the reference group) consisted of a concurrent sample of 104 CRYO-ROP study participants at the Philadelphia study center who did not develop ROP during the neonatal period.20,21 One hundred two (98.1%) of these children returned for the 10-year follow-up examination and responses to the HUI3 questionnaires were obtained from the parents of all 102 children. This study was approved by the institutional review boards at all participating institutions and written informed consent was obtained from parents/guardians at study enrollment, prior to randomization, and prior to each follow-up phase. For some analyses, children in the randomized group were subdivided into a “blind/low vision” group and a “sighted” group. The blind/low vision group consisted of 86 children whose parents provided complete HUI3 results and 1 child whose parents failed to provide data for the emotion and cognition attributes of the HUI3. All had visual acuity (VA) scores in the better eye that were classified as an unfavorable outcome in the CRYO-ROP study.19,21 This included VA of 20/200 or worse as measured by the Early Treatment Diabetic Retinopathy Study (ETDRS) distance VA charts (n=13).19,23,25 Grating acuity worse than 6.4 cycles per degree as measured by the Teller acuity card procedure (n=13)19,23 or by vision too poor to be measured with the ETDRS charts or the Teller acuity cards (minimal pattern vision, defined as detection of the 2.2-cm-wide stripes on the Low Vision Teller acuity card, light perception only, or no light perception) (n=36). The sighted group consisted of 157 children (64.3%) who had VA classified as a favorable outcome in the CRYO-ROP study.19 One hundred fifty-four had VA at age 10 years that was better than 20/200 in at least 1 eye when tested with ETDRS logarithm of the minimum angle of resolution (logMAR) distance VA charts.19,20 Three additional children in the sighted group were not testable with the ETDRS charts but had VA of 6.4 cycles per degree or better when tested with the Teller acuity card procedure.19,25 Among the 102 children in the no-ROP group, all but 1 child had VA better than 20/200 in both eyes and were testable with the ETDRS charts. The 1 child who could not be tested with the ETDRS charts provided Teller acuity card results of 9.6 cycles per degree in the better eye, indicating that it was appropriate to consider this child as “sighted.”

**PROCEDURES AT THE 10-YEAR STUDY EXAMINATION**

A complete eye examination was performed by a study-certified ophthalmologist. Monocular VA, with spectacle correction if needed, was measured by 1 of 2 study-certified testers who were masked to the treatment status and current ocular condition of the child’s eyes.19 The tester performed a standardized protocol using ETDRS logMAR distance VA charts.19,20 If the child could not be tested with the ETDRS chart, monocular grating acuity was assessed using the Teller acuity card procedure.19,25

**INTERVIEW PROTOCOL**

Parents or caregivers of the children were interviewed by study personnel who had been trained (by S.S.) in the administration of the questionnaire. The interviewers followed a written script (based on the HUI3 Classification System) that was administered in exactly the same order to all respondents.20,21 The health status was measured from the perspective of the parent or guardian proxy respondents who reported both the health and the functional level within each attribute according to their best judgment. The interview for measuring the health status took less than 10 minutes for each study participant.

**MEASUREMENT OF HEALTH STATUS**

The HUI Classification System was used to report the health status of the subjects.6,9,30 The HUI is a generic, comprehensive, valid, and reliable system. It has demonstrated the capability of discriminating among levels of functional deficits among children with cancer31,32 and a population of ELBW school-aged children and controls.4,5 In the current study, the version of the system used was the HUI3 Classification System, which superseded the HUI2 Classification System used in the earlier studies.4,5,26,31,32 The HUI3 Classification System consists of 8 attributes: vision, hearing, speech, ambulation, dexterity, emotion, cognition, and pain. These attributes were empirically selected from a list of 15 attributes considered most important by parents and children.31 Each attribute has either 5 or 6 defined levels of severity, ranging from normal function to severe dysfunction (Table 1). The health status of a particular patient may be described as a profile by an 8-element vector (x1, x2, ..., x8, in which xi describes the level of functioning [1-5 or 1-6] for attribute i).
Table 1. Multiattribute Health Status Classification System: Health Utilities Index Mark 3

<table>
<thead>
<tr>
<th>Attribute</th>
<th>Level Description</th>
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</thead>
</table>
| Vision    | 1. Able to see well enough to read ordinary newsprint and recognize a friend on the other side of the street, without glasses or contact lenses.  
2. Able to see well enough to read ordinary newsprint and recognize a friend on the other side of the street, but with glasses.  
3. Able to read ordinary newsprint with or without glasses but unable to recognize a friend on the other side of the street, even with glasses.  
4. Able to recognize a friend on the other side of the street with or without glasses but unable to read ordinary newsprint, even with glasses.  
5. Unable to read ordinary newsprint and unable to recognize a friend on the other side of the street, even with glasses.  
6. Unable to see at all. |
| Hearing   | 1. Able to hear what is said in a group conversation with at least 3 other people, without a hearing aid.  
2. Able to hear what is said in a conversation with 1 other person in a quiet room without a hearing aid, but requires a hearing aid to hear what is said in a group conversation with at least 3 other people.  
3. Able to hear what is said in a conversation with 1 other person in a quiet room with a hearing aid, and able to hear what is said in a group conversation with at least 3 other people, with a hearing aid.  
4. Able to hear what is said in a conversation with 1 other person in a quiet room, without a hearing aid, but unable to hear what is said in a group conversation with at least 3 other people, even with a hearing aid.  
5. Able to hear what is said in a conversation with 1 other person in a quiet room with a hearing aid, but unable to hear what is said in a group conversation with at least 3 other people, even with a hearing aid.  
6. Unable to hear at all. |
| Speech    | 1. Able to be understood completely when speaking with strangers or friends.  
2. Able to be understood partially when speaking with strangers but able to be understood completely when speaking with people who know me well.  
3. Able to be understood partially when speaking with strangers or people who know me well.  
4. Unable to be understood when speaking with strangers but able to be understood partially by people who know me well.  
5. Unable to be understood when speaking to other people (or unable to speak at all). |
| Ambulation | 1. Able to walk around the neighborhood without difficulty, and without walking equipment.  
2. Able to walk around the neighborhood with difficulty, but does not require walking equipment or the help of another person.  
3. Able to walk around the neighborhood with walking equipment, but without the help of another person.  
4. Able to walk only short distances with walking equipment, and requires a wheelchair to get around the neighborhood.  
5. Unable to walk alone, even with walking equipment. Able to walk short distances with the help of another person, and requires a wheelchair to get around the neighborhood.  
6. Cannot walk at all. |
| Dexterity | 1. Full use of 2 hands and 10 fingers.  
2. Limitations in the use of hands or fingers, but does not require special tools or help of another person.  
3. Limitations in the use of hands or fingers, is independent with use of special tools (does not require the help of another person).  
4. Limitations in the use of hands or fingers, requires the help of another person for some tasks (not independent even with use of special tools).  
5. Limitations in use of hands or fingers, requires the help of another person for most tasks (not independent even with use of special tools).  
6. Limitations in use of hands or fingers, requires the help of another person for all tasks (not independent even with use of special tools). |
| Emotion   | 1. Happy and interested in life.  
2. Somewhat happy.  
3. Somewhat unhappy.  
4. Very unhappy.  
5. So unhappy that life is not worthwhile. |
| Cognition | 1. Able to remember most things, think clearly, and solve day-to-day problems.  
2. Able to remember most things, but have a little difficulty when trying to think and solve day-to-day problems.  
3. Somewhat forgetful, but able to think clearly, and solve day-to-day problems.  
4. Somewhat forgetful and has a little difficulty when trying to think or solve day-to-day problems.  
5. Very forgetful, and has great difficulty when trying to think or solve day-to-day problems.  
6. Unable to remember anything at all, and unable to think or solve day-to-day problems. |
| Pain      | 1. Free of pain and discomfort.  
2. Mild to moderate pain that prevents no activities.  
3. Moderate pain that prevents a few activities.  
4. Moderate to severe pain that prevents some activities.  
5. Severe pain that prevents most activities. |

*Level descriptions are worded here exactly as presented to respondents in the Health Utility Index Mark 3 preference measurement survey (adapted from Feeny et al30).*

Results from each of the 8 attributes were classified as “normal,” that is, no functional limitations on any of the several levels of functional limitations, or “abnormal” (Table 1). For the 8 attributes, normal was defined as follows:

1. **Vision**: Able to see well enough to read ordinary newsprint and recognize a friend across the street, with (level 2) or without (level 1) glasses. (In view of the high prevalence of high refractive errors in the participants of this study, we elected to consider levels 1 and 2 of the HUI3 Classification System as normal when describing the population for this attribute. However, for calculation of utility scores, levels 1 and 2 were entered separately into the equation.)

2. **Hearing**: Able to hear what is said in a group conversation with at least 3 other people, without a hearing aid (level 1).
structural independence. Thus, a child who is blind may have difficulty and without walking equipment (level 1). Similarly, dexterity may be normal although the child may be unable to exercise it owing to blindness.

DATA ANALYSIS

As utility scores are continuous measures with interval scale properties, these data are reported as mean and standard deviation of the group mean. The statistical significance of the distribution differences in the HRQL scores between the groups was assessed using the 2-sample Wilcoxon rank sum (Mann-Whitney) test.

Table 2 provides demographic information for the randomized and no-ROP groups of children, as well as for the subgroups of blind/low vision and sighted children who comprised the randomized group. As reported previously, although all children in both groups had to be less than 1251 g birth weight, children who developed threshold ROP and participated in the randomized trial had mean lower birth weights and mean gestational ages than did study participants who did not develop ROP. Children in the randomized group who had favorable VA in at least 1 eye at age 10 years had birth weights that were higher than those of children who were in the blind/low vision group. However, the remaining demographic characteristics were similar for the 2 subgroups of children in the randomized trial, though they differ in comparison to children in the no-ROP group in racial demographics and in whether they were born in a study hospital (inborn vs outborn). Table 2 also gives the median VA scores of children in each group and indicates that the median VA of the children in the sighted-randomized group, all of whom were classified as having favorable VA outcomes for the primary study analysis, was poorer than the median VA of the children in the no-ROP group.

### Table 2. Demographic Description of Study Participants, Including Information on Visual Acuity at 10-Year Examination

<table>
<thead>
<tr>
<th>Variable</th>
<th>All (N = 244)</th>
<th>Who Are Blind or Who Have LV in the Better Eye (n = 87)</th>
<th>Who Are Sighted in the Better Eye (n = 157)</th>
<th>No-ROP Subjects (n = 102)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Birth weight, mean (SD), g</td>
<td>800 (166)</td>
<td>771 (160)†</td>
<td>817 (168)‡</td>
<td>1062 (141)</td>
</tr>
<tr>
<td>Gestational age (SD), wk</td>
<td>26.3 (1.8)</td>
<td>26.1 (1.8)</td>
<td>26.5 (1.7)</td>
<td>29.6 (2.0)</td>
</tr>
<tr>
<td>Race, %</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>White</td>
<td>69.3</td>
<td>66.7</td>
<td>70.7</td>
<td>36.3</td>
</tr>
<tr>
<td>Black</td>
<td>19.3</td>
<td>14.9</td>
<td>21.7</td>
<td>58.8</td>
</tr>
<tr>
<td>Other</td>
<td>11.5</td>
<td>18.4</td>
<td>7.6</td>
<td>4.9</td>
</tr>
<tr>
<td>Sex, % male</td>
<td>48.0</td>
<td>47.1</td>
<td>46.4</td>
<td>43.1</td>
</tr>
<tr>
<td>Inborn, % of subjects</td>
<td>63.9</td>
<td>63.2</td>
<td>64.3</td>
<td>93.1</td>
</tr>
<tr>
<td>Multiple births, % of subjects</td>
<td>23.8</td>
<td>16.1</td>
<td>28.0</td>
<td>19.6</td>
</tr>
<tr>
<td>Median VA (25th percentile, 75th percentile)</td>
<td>20/63 (20/32, blind)</td>
<td>Blind (blind, blind)</td>
<td>20/40 (20/25, blind)</td>
<td>20/20 (20/20, 20/25)</td>
</tr>
</tbody>
</table>

Abbreviations: LV, low vision; ROP, retinopathy of prematurity; VA, visual acuity.

*Unfavorable, VA 20/200 or worse by Early Treatment Diabetic Retinopathy Study charts, worse than 6.4 cycles per degree by Teller acuity cards, or minimal pattern vision, light perception only, or no light perception.

†One child in this group had Health Utilities Index Mark 3 results on only 6 of the 8 attributes.
‡Favorable, better than 20/200 VA by Early Treatment Diabetic Retinopathy Study charts, or 6.4 cycles per degree or better by Teller acuity cards.

3. Speech: Able to be understood completely when speaking with strangers or friends (level 1).
4. Ambulation: Able to walk around the neighborhood without difficulty and without walking equipment (level 1).
5. Dexterity: Full use of 2 hands and 10 fingers (level 1).
7. Cognition: Able to remember most things, think clearly, and solve day-to-day problems (level 1).

The above HUI3 Classification System can be linked directly with preference-based scoring models called “multiattribute utility functions.” This system converts descriptive measures of ability or disability within each attribute obtained from respondents into a measure of overall HRQL based on a mathematical utility formula developed by Torrance and colleagues. The formula for HUI3 was developed in 1994 using preference measurements collected from a random sample of 504 adults living in Hamilton, Ontario, using a combination of the Visual Analog Scale (feeling thermometer) and Standard Gamble Technique (chance board). The HRQL score obtained, thus, is an estimate of the score that would be obtained had utility for the health state been measured directly from a random sample of the general population using the Standard Gamble technique.

The HUI3 multiattribute utility scores provide a spectrum from 0.00 (“dead”) to 1.00 (“perfect health”). The HUI3 scale is defined for the interval –0.36 to 1.00. Negative scores represent states considered “worse than dead.” Further details on the calculation of HRQL scores are described elsewhere.
Based on interviews with parents or guardians, Figure 1 shows the proportion of children with functional limitations at any level in each of the 8 attributes of the HUI3 for the blind/low vision and sighted subgroups of children in the randomized cohort and for the no-ROP reference group. In 5 of the attributes (vision, hearing, speech, ambulation, and dexterity), the no-ROP group had minimal functional limitations (<4.0% for each attribute). In contrast, parents or guardians of the children in the randomized group who were blind or had low vision reported high rates of functional limitation in vision (94.3%), speech (42.5%), ambulation (51.7%), and dexterity (32.2%) in their children. The corresponding figures for the children in the randomized group who were sighted indicated lower rates of functional limitations ranging from 4.5% for dexterity to 16.6% for ambulation. Rates of functional limitation in the hearing attribute were similar: 3.4% for the blind/low vision–randomized group and 3.8% for the sighted-randomized group.

Rates of functional limitations reported by parents or guardians for the cognition attribute were high for all 3 groups of children. Parents or guardians of nearly one third (31.4%) of children in the no-ROP group, almost two thirds (64.0%) of children in the randomized group who were blind/low vision, and half (51.0%) of children in the randomized group who were sighted indicated that their children had functional limitations in the cognition attribute.

Rates in the pain attribute were similar for all 3 groups while rates in the emotion attribute were similar for the no-ROP reference group (13.7%) and the sighted-randomized group (15.3%), but somewhat higher (23.6%) for children in the blind/low vision randomized group. Table 3 provides information on the frequencies of the number of attributes that are affected in the individual child for the randomized and no-ROP cohorts. Two (2.3%) of 86 children in the blind/low vision–randomized group, approximately one third of children in the sighted-randomized group, and half of children in the no-ROP group were judged by parents or guardians to be normal for all 8 attributes. The proportion of children in the blind/low vision–randomized group whose parents or guardians indicated limitations for 4 or more attributes was 46.5%, in contrast to 6.4% for children in the sighted-randomized group and 2.0% for children in the no-ROP group.

Table 4 gives a description of overall HRQL scores of children for the randomized and no-ROP cohorts. Median HRQL score for the blind/low vision–group (0.27) is significantly lower than the median HRQL score for the sighted-randomized group (0.87, P<.001). Although the median score for the sighted-randomized group is significantly lower than the median HRQL score for the no-ROP reference group (0.97, P<.001), the difference is much smaller. All 3 groups of children showed a broad range of scores, from below 0 to 1.00, despite differences in median scores.

Figure 2 shows the variability in the distribution of HRQL scores within the blind/low vision–randomized, sighted-randomized, and no-ROP reference groups. In the blind/low vision–randomized group, very few children had HRQL scores above 0.65, and most children had scores in the lower ranges, including a substantial proportion with scores below 0. In contrast, a substan-
tial proportion of children in the sighted-randomized group and most children in the no-ROP group had scores above 0.65. Twenty-five children (29.1%) in the blind/low vision–group, 2 children (1.3%) in the sighted-randomized group, and the 1 child (1.0%) in the no-ROP reference group had scores that were below 0.

In a study of HRQL in 8-year-old children, Saigal and colleagues found significantly lower HRQL scores for pre-term children with birth weights less than 1000 g compared with a group of full-term children of the same age (median HRQL score 0.88 vs 1.0, P<.0001). However, few children in this cohort had significant visual morbidity. The present study evaluated HRQL in 2 groups of 10-year-old preterm children with birth weights less than 1251 g and found that the HRQL scores were related both to the presence of threshold ROP and to the visual outcome following threshold ROP. Overall, the highest HRQL scores were found for the group of children who did not develop ROP, who, on average, had birth weights that were 262 g higher and gestational ages that were 3.3 weeks greater than those of children with ROP in the randomized group, despite similar enrollment criteria. This is reflective of the nature of ROP that is more prevalent and more severe in the most immature infants. Furthermore, the higher HRQL scores in the no-ROP reference group may reflect the better visual acuities that were found in this group of children (Table 1), as well as their somewhat increased maturity at birth compared with the children in the randomized group.

The lowest HRQL scores were observed in those children who developed threshold ROP in the neonatal period and were bilaterally severely visually impaired or blind. The group of children who developed severe ROP in the neonatal period and retained VA better than 20/200 showed a pattern of HRQL results that resembled those of children in the no-ROP reference group, albeit with a lower median score and a broader distribution of scores, even though they had an mean birth weight of only 817 g, an average gestational age of only 26.5 weeks, and median VA 20/40 in comparison to the median VA of 20/20 in the no-ROP group.

Within the group who developed threshold ROP, there was a marked difference in both the median scores and the distribution of scores between those children who had VA of 20/200 or worse in both eyes (blind/low vision) and those who had VA that was better than 20/200 in at least 1 eye (sighted) (Figure 2). In fact, the distribution of HRQL scores for the sighted-randomized group was more similar to that in the no-ROP reference group than it was to the distribution of scores in the blind/low vision–randomized group. Scores greater than 0.95, which are associated with, for example, having to wear glasses but otherwise being in perfect health, were found in 33.8% of children in the sighted-randomized group and in 52.0% of children in the no-ROP reference group, but in only 2.3% of children in the blind/low vision randomized group. At the lower end of the distribution, 1.3% of children in the sighted-randomized group and 1% of children in the no-ROP group had scores that were below 0, in comparison to 29.1% of

Figure 2. Distribution of health-related quality-of-life (HRQL) scores for the health states of the 86 children in the randomized (RZ-blind/low vision) group who had visual acuity of 20/200 or worse at age 10 years and complete Health Utilities Index Mark 3 results, the 157 children in the randomized group (RZ-sighted) who had 1 or more sighted eyes at age 10 years, and the 102 children with birth weights less than 1251 g who did not develop ROP (No ROP/reference group) and who were participants at one study center in the natural history portion of the multicenter trial of Cryotherapy for Retinopathy of Prematurity study.

Table 4. Summary of HRQL Scores for the ROP Randomized Group and No-ROP Group

<table>
<thead>
<tr>
<th>Variable</th>
<th>Randomized Subjects</th>
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<th></th>
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</thead>
<tbody>
<tr>
<td></td>
<td>All (N = 243)</td>
<td>Who Are Blind or Who Have LV in the Better Eye (n = 86)*</td>
<td>Who Are Sighted in the Better Eye (n = 157)</td>
<td>No-ROP Subjects (n = 102)</td>
</tr>
<tr>
<td>Median (range)</td>
<td>0.72 (−0.36 to 1.00)</td>
<td>0.27 (−0.36 to 1.00)</td>
<td>0.87 (−0.24 to 1.00)</td>
<td>0.97 (−0.01 to 1.00)</td>
</tr>
<tr>
<td>Mean (SD)</td>
<td>0.59 (0.38)</td>
<td>0.25 (0.37)</td>
<td>0.78 (0.25)</td>
<td>0.90 (0.16)</td>
</tr>
<tr>
<td>HRQL&lt;0 (*“worse than dead”, No. (%) of subjects</td>
<td>27 (11.1)</td>
<td>25 (29.1)</td>
<td>2 (1.3)</td>
<td>1 (1.0)</td>
</tr>
</tbody>
</table>

Abbreviations: HRQL, health-related quality-of-life; LV, low vision; ROP, retinopathy of prematurity.

*The number of children differs by 1 from Table 1 because parents of 1 child provided data on only 6 of 8 attributes that make up the Health Utilities Index Mark 3 score.

†P<.001 between blind/LV and sighted-RZ subjects.

‡P<.001 between sighted-RZ group and No-ROP group.
children in the blind/low vision randomized group. Thus, nearly one third of children in the blind/low vision-randomized group had scores indicating the health status of the child was viewed as being worse than dead.

The utility formula applied to the aforementioned data was based on the perspective of adults in the general population. The HRQL scores of the children in the current study might have been higher had the preferences been elicited directly from the children. Furthermore, many of the low scores obtained in the present study might well be because of the perception of the adults from the general population, from whose preferences the formula was derived, that blind children would likely have poor functioning in their daily lives. In another study, Saigal and colleagues interviewed 12- to 16-year-old ELBW adolescents (and their parents) to determine their health status and measured preferences with the chance board. The results showed HRQL results that were fairly positive, even though a significant proportion of the children had been diagnosed as having neurosensory impairments. Saigal et al suggested that the children and their parents may have learned to accept their disabilities and may have recalibrated their personal expectations. Although utility scores obtained from patients and/or parents are clearly relevant for decision making at an individual level, utility scores based on community or general public values, as used in the current study, may be more appropriate for assessing the efficacy of interventions and for allocation of health care resources for clinical programs.

Another way of comparing HRQL outcome among the 3 groups is to examine the number of attributes in which the parents or guardians judged that functional limitations were present (Table 3). In the blind/low vision–randomized group, only a very small percentage of children were judged to have no attributes affected, while one third of the sighted-randomized and more than half of the no-ROP group were judged to have no attributes affected. Thus, the HRQL scores among the sighted-randomized group were closer to those of the no-ROP reference group than to those in the blind/low vision–group. This similarity between the sighted-randomized and no-ROP groups, despite differences in the birth weights, gestational ages, and VAs of the children, is likely owing to the lower burden of visual and other associated morbidities in the sighted group compared with the blind/low vision–group. Furthermore, it is possible that the differences in VA between the sighted-randomized group (median VA 20/40) and the no-ROP group (median VA 20/20) are of little consequence in the quality of everyday life of a 10-year-old child.

An encouraging finding for the blind/low vision–group is that despite the very low HRQL scores in many children in this group, more than 25% of these children were judged by their parents or guardians to have functional limitations in only 1 attribute (Table 3), and in 22 of 157 of these children the single attribute that showed a functional limitation was vision. It is not surprising that some of the substantial differences in HRQL scores shown by the sighted vs the blind/low vision–subgroups of children who had a history of threshold ROP are likely to be compounded by the sequelae of perinatal morbidities in this immature population. That is, low vision or blindness may not be the only cause of poor health sta-
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